

# The Untold Story of Being Designated an Alternate Level of Care Patient

## Ce qu'on ne dit pas sur le fait d'être désigné pour un autre niveau de soins



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### Abstract

*Introduction:* Much of the research and policy reports on Alternate Level of Care (ALC) in Canada have focused on the impact ALC has on acute care services. To date, the experiences and opinions of those who must wait in hospital for alternate services have been largely absent from discussions.

*Method:* A qualitative study was conducted with patients and families designated as ALC in one urban and two rural hospitals in Atlantic Canada. Data were analyzed using content analysis.

*Results:* Three themes emerged from the data: a perception of normalcy, being old but not sick and anticipating relocation to another facility.

*Conclusions:* ALC is an important issue for patients and their families. Policy directives aimed at addressing the causes and impacts of ALC, identification and provision of appropriate supportive care in the community and sensitivity to the impact of ALC for individuals designated as ALC are needed.

## Résumé

*Introduction :* La plupart des recherches et des rapports de politiques sur les autres niveaux de soins (ANS), au Canada, ont trait à leur impact sur les soins de courte durée. À ce jour, l'expérience et l'opinion de ceux qui doivent attendre à l'hôpital pour obtenir d'autres services ont été plutôt absentes des discussions sur le sujet.

*Méthode :* Une étude qualitative a été menée auprès de patients (et leurs familles) désignés pour un ANS dans un hôpital urbain et deux hôpitaux ruraux du Canada atlantique. Les données ont été traitées au moyen de l'analyse du contenu.

*Résultats :* Trois thèmes se dégagent des données : une perception de normalité, le fait d'être vieux sans être malade et l'attente d'un transfert vers un autre établissement.

*Conclusions :* L'ANS est un enjeu important pour les patients et leurs familles. Il est nécessaire de doter les politiques de directives qui permettent d'aborder les causes et l'impact de l'ANS, d'identifier et d'apporter les soins de soutien appropriés dans la communauté et de tenir compte de la sensibilité à l'impact chez tous les patients désignés pour un ANS.

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THERE HAS BEEN INCREASING CONCERN OVER THE GROWING NUMBER OF PEOPLE who must wait in hospital for more appropriate settings to have their needs met. The Canadian Institute of Health Information (CIHI) refers to the level of care required by these individuals as Alternate Level of Care (ALC). To be classified as ALC, there must be a notation on the patient's hospital record indicating that the person no longer requires acute care services (CIHI 2009). Although there has been concern about the consistency of data reported on patients designated as ALC (Cancer Care Ontario 2011; CIHI 2009), there is a general consensus that ALC is a complex issue that negatively impacts hospitals' ability to operate efficiently (Canadian Health Services Research Foundation 2011; CIHI 2012; Costo et al. 2012; Sutherland and Crump 2013).

Across Canada, clinicians and policy makers have been struggling to understand ALC from both a system and individual perspective. CIHI has produced several reports on ALC over the years with the hope of "understanding the extent of the ALC challenge in hospitals" (CIHI 2009, 2012; Walker et al. 2009). Others have attempted to explore possible strategies to respond and reduce ALC within Canadian hospitals (Costa and Hirdes 2010; Ontario Hospital Association 2012; Sutherland and Crump 2011; Walker 2011). Despite these efforts, ALC continues to be of concern, with reports of as many as 25% of acute care beds being occupied by people designated as ALC (McCloskey et al. 2014).

Notably absent from discussions on ALC is the patients' perspective. Yet, if the goal of ensuring Canadians receive the right care in the right place is to be achieved, those affected by ALC must be heard. Patients and their families have first-hand knowledge of the issues surrounding ALC and by drawing on these experiences, policy makers and clinicians may have a better understanding of how to respond to ALC. The purpose of this study was to speak with ALC patients and their family members to understand the ALC experience from their unique perspective.

## Methods

A qualitative study was conducted with hospital patient's and family members who were designated as ALC. Open-ended interviews were conducted to collect data about the ALC experience and questions such as "what is it like to be waiting in hospital" and "tell me more about that" were used. Data were analyzed using content analysis. The focus of content analysis is to discover the underlying meaning and significance of an experience from the perspective of those directly affected (Hsieh and Shannon 2005; Rodgers 2000).

## Sample

The study utilized a convenience sample of patients designated as ALC and their families in New Brunswick, Canada. Participants were recruited from one regional and two community hospitals within one health authority. When the study was initiated, 118 patients were classified as ALC in the three hospitals, including 92 (20.7%) in the regional hospital and 16 (35.6%) and 10 (40.0%) in the community facilities.

Hospital staff distributed letters of invitation to patients and families of people designated as ALC who were English-speaking and able to provide informed consent. A research assistant met with those who expressed interest in the study to explain the study and to answer questions. All 20 people who expressed an interest in the study agreed to participate (Table 1). Half (10) of these participants were from the regional facility and half were from one of the two community facilities. All interviews took place between May 2012 and November 2012.

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**TABLE 1.** Study participants

Patients (n = 16)	
Admitted to hospital through the emergency department	16
Mean age	85.1 years (SD = 11.1)
<b>Sex</b>	
Male	5 (31.3%)
Female	11 (68.7%)
<b>Admission diagnosis</b>	
Dysphagia	1
Pain	1
Urinary tract infection	1
Cardiac	3
Respiratory	2
Social admission	2
Fall	3
Neurological	2
Cellulitis	1
<b>Living arrangements prior to admission</b>	
Home with family	10 (62.5%)
Home alone	6 (37.5%)
Formal supports prior to admission	9 (56.3%)
<b>Discharge plan</b>	
Long-term care facility (nursing home)	15 (93.7%)
Special care home*	1 (6.3%)
Family members (n = 4)	
Husband	1
Daughter	1
Son	1
Friend	1

\*A special care home is a 24-hour assisted living facility staffed by unregulated workers.

## Data collection

All interviews took place in an in-patient hospital room and were tape-recorded and transcribed verbatim. Participants were encouraged to discuss the events that led to the current hospital admission and what it was like to be in hospital or to have a loved one in hospital for a prolonged stay. Interviews ranged from 20 to 45 minutes in length. Data were entered in NVivo 7, and a constant comparison analysis was used to analyze data. The study was approved by the Research Ethics Boards at University of New Brunswick Saint John and Horizon Health Network.

## Findings

Three themes emerged from the data, including a perception of normalcy, being old but not sick and anticipating relocation to another facility.

### *Perception of normalcy*

Life was described by 18 participants prior to the hospitalization as one of a decline in physical function and difficulty in managing at home. With the exception of one patient, ALC patients and the family members were satisfied with their pre-hospitalization living conditions, despite the fact that 12 patients/family members described a home situation that was marked by compromised safety, social isolation and increasing dependency. Thom, the husband of one ALC patient, described how he “lifted” his wife “in and out of bed every day” and how she would “roll out of the bed or slip out of the chair or slip out of the bed.” Frank, a 55-year old with a debilitating neurological condition, talked about being confined to his home for two years prior to admission to hospital because of functional impairment and reliance on his sister to “get my mail, get my groceries, and wash all my clothes.”

Ten participants spoke of their trust in the healthcare system and of their perception that a healthcare provider was aware of their living situation pre-hospitalization. The underlying assumption was their living situations were “normal” and that initiation/augmentation of supportive services was not required because the need was never introduced by a healthcare provider. John described the home care nurse who came to his house to monitor his wife’s colostomy by saying, “she was aware she was spending her days and nights in that chair and didn’t do anything, so I just assumed it was normal.” Even those who did not have community supports in place prior to the hospitalization did not consider services because they were unaware of what was available or because they were waiting for a healthcare professional to direct them to do so. When Thom was asked about lifting his wife in and out of bed and picking her up off the floor, he responded by saying that the healthcare professionals who were involved in his wife’s care were “aware of what we were dealing with at home.”

Every family participant spoke of an unquestioned role of providing informal care to the patient that was marked by a gradual increase in emotional and physical demands. Each family member interviewed accepted the fact that they played a central role in their loved one’s ability to remain at home for as long as they did. Surprisingly, family members did not feel relieved of their duties as caregivers after their loved ones were hospitalized. Family members continued to visit frequently and support their family member who was designated as an ALC patient. Mary, whose mother was in hospital for five months at the time of the interview, stated: “I work Saturday, Sunday, Monday and Tuesday and then I have Wednesday, Thursday and Friday off so I come here in the city and I stay with my family so I can visit with Mom.”

With the exception of one participant, all spoke matter-of-factly about the ALC status. They acknowledged that the demand for long-term care beds seemed to exceed the supply. They accepted the fact that they would have lengthy hospital stays before “getting to the top of

a [nursing home] list.” Seven participants were aware of other ALC patients who were waiting longer than themselves for a bed in a long-term care facility.

### *Old but not sick*

A reoccurring topic in the interviews was the feeling that they were using a hospital bed unnecessarily, which participants were aware were in short supply. Although most participants spoke of “being sick” during the early days of the hospitalizations, all four family members and eight patients were mindful of the fact that they no longer required acute hospital services but were unable to leave the hospital because of the unavailability of long-term care services. For these 12 participants, the need to occupy a hospital bed unnecessarily was a source of guilt. Under these conditions, participants spoke of often engaging in activities that minimized the work they created for staff, thus not taking valuable time away from “the sick patients.” One participant said she rarely left her room during her 11-month hospitalization because it would require the staff’s assistance; another spoke of accepting a bedpan rather than walking to the bathroom because it “was easier for the nurses.”

Participants appeared to be acceptant of the fact that “not being sick” meant patients designated as ALC were not a priority for staff and therefore not deserving of staff’s time or attention. Several participants talked about the staff “always being in a rush” and not always having time to engage in meaningful dialogue or to meet some of the patients’ basic needs. Alice, a lady who had been designated as ALC for three months, described her frustration in getting a regular bath:

I do realize that some people need more attention than others. But you’re only allowed a bath every so often. They couldn’t fit everybody in.

I’m going to beg for a bath tomorrow because really you only get one [a bath] once a week if you’re lucky.

Nine participants discussed the financial implications of being in hospital when they were not sick. Every family member interviewed discussed the charges their loved one incurred as a result of waiting in hospital for alternate services. Family members compared the monthly hospital fees associated with those they will incur when their loved one moves into a long-term care facility. None of the family members disputed the monthly charges and one family member referred to the expenses as a “win-win. This way she gets looked after while she waits, and we pay for the care she gets.” Alternately, participants were less acceptant of the expenses associated with family members’ regular hospital visits, including gas and parking expenses. These expenses created financial and emotional difficulties for some participants. One family member stated: “It costs me about \$38.00 a day. I was coming [to visit] every day but I can’t afford to anymore.” Five participants anticipated these expenses would decrease after entry

into a long-term care facility home because of the expectation of placement in a facility within their own community and the absence of parking fees.

### *Anticipating relocation to a long-term care facility*

Only one of the participants was apprehensive about the pending relocation to a long-term care facility. Although most admitted initially resisting the idea of long-term care, at the time of the interviews, every participant was anxious to leave the hospital and to move into a long-term care facility. Eight participants were so eager to enter long-term care that they described efforts in trying to expedite the process, with the most frequent activity being regular phone calls to their chosen facility and contacting friends and people perceived to have influence in placement decisions. Some talked about calling the Director of Nursing in their preferred facility, and one reported calling a family friend who worked in their preferred facility. When asked about contacting the facilities, three participants admitted being “advised by a staff member” to make regular phone calls, as one family member stated: “they said to call at least once a week because the homes pick who they admit. If you call, they are less likely to forget about you and you might get a bed quicker.” However, sometimes, this strategy was not effective, as one daughter stated that staff in her mother’s preferred facility were no longer accepting her calls:

Well, they told us here that we should call the home every week and ask them how much longer mum has to wait. They won’t accept my calls anymore, guess they are tired of hearing from me. But I keep calling anyway.

When asked about what they thought it would be like to live in a long-term care facility, participants described a life where they would have more autonomy, improved quality of life and less social isolation. Many believed the routines of the hospital would not exist in a long-term care setting. They anticipated life would be flexible and staff would have more time to spend with them. One participant was looking forward to the daily baths she would get when she finally entered the long-term care facility; others believed that long-term care would help them to regain some of the functional ability lost during the long hospital stay, and still others were looking forward to the social stimulation.

## **Discussion**

Although it is widely recognized that ALC is an important issue for healthcare administrators and policy makers, what this study highlights is that ALC is an equally important issue for patients and families. The patients who were designated as ALC in this study were waiting up to 11 months in hospital for long-term care services, and some spoke of other people designated as ALC who were waiting much longer than themselves. While patients and family members likely have different perspectives regarding being designated as an ALC patient, the issues they discussed during the interviews were strikingly similar. It is noteworthy that

lengthy waits for long-term care for both patients and families have become normalized – they were largely unquestioned by participants. This finding is consistent with that of others who assert that limited access to long-term care is a key factor in the ALC issue (Costa and Hirdes 2010; Zhang et al. 2012). Although wait times within the Canadian healthcare system are frequently discussed and monitored, these discussions are generally limited to acute care services (Shamian et al. 2006). Access to long-term care has been largely ignored in governmental wait-time policies. This may be owing to the fact that long-term care does not fall under the *Canada Health Act* and, therefore, is not subject to the same level of political scrutiny as publicly funded hospital services. Yet, for many Canadians, long-term care is a necessary component of healthcare (CIHI 2013).

Limited access to long-term care services is not only an issue impacting those waiting for a nursing home bed, but also has a significant effect on those requiring acute care in hospitals. According to CIHI (2011), on any given day, there are upwards of 7,550 Canadian hospital beds occupied by people who are waiting for long-term care services. In other words, access to an acute care hospital bed is compromised for 7,550 Canadians each day because of the unavailability of a hospital bed. Limited access to long-term care is an issue that has far-reaching effects and deserves the same attention as the pan-Canadian priority areas identified in the 2004 Health Accord (Government of Canada 2006). Until improvements are made in accessing long-term care services, hospitals will continue to struggle with trying to achieve targets set for wait times in the identified priority areas.

In the province where this study took place, individual facilities choose who they will admit from a provincially approved long-term care wait-list. Selection from this list is based on an individual facility's perception of their ability to meet an individual's needs and not on wait times or individual circumstances. The fact that participants were advised to make regular phone calls to their preferred facility to ensure they were "not forgotten about" suggests healthcare providers were concerned about the wait-list management process in place. Surprisingly, family members did not question the recommendation of making regular phone calls. It is possible that making regular contact with the preferred facility helped family members to feel they were contributing to the admission process. A review of long-term care wait-list management processes found wait-list policies generally involve some combination of need and first-come-first-serve philosophies (Chafe et al. 2010). The effectiveness of facility-based management of long-term care wait-lists has been largely ignored in the literature. There may be benefit in exploring alternate strategies to manage the wait list for long-term care within the province where this study took place.

Home care is often cited as a possible alternative to ALC (Health Council of Canada 2012). It is estimated that over one million Canadians currently receive publicly funded home care services (Canadian Home Care Association 2015). McCloskey and colleagues (2014) recently reported that 46.2% of patients designated as ALC received publicly funded home care prior to being hospitalized. An estimated 53.3% of the home care

provided in provinces contributing to the 2013–2014 CIHI home care reporting system was initiated during a hospital admission (CIHI 2014). Yet, the provincial nature of home care compromises its ability to serve as a national response to ALC. For example, each province has its own unique basket of home care services that vary by type of service available. In addition, while residents in some provinces are subjected to income-testing to assess eligibility for publicly funded home support, those in other provinces may be eligible irrespective of income or assets (Blomqvist and Busby 2012; Mery et al. 2014). New Brunswick residents must undergo an income assessment to identify eligibility for publicly funded services and a functional assessment to determine the amount of service. Residents of New Brunswick may qualify for publicly funded home care in the form of supportive home services for a maximum of 7 hours per day or 49 hours per week. The broad range of terminology, services, funding structures as well as the different methods of assessment used to determine eligibility are major obstacles in comparing this level of home care with that available across the country (Health Council of Canada 2012). Irrespective of the differences that exist, there are no guarantees that home care will be available or sufficient to meet the needs of those designated as ALC. Home care should not be provided as an alternative to ALC solely because it is more convenient and possibly less expensive. Rather, home care should be available only because it is the most appropriate option based on individual need.

Contrary to existing literature on wait times (Harold and Jackson 2011; Webster et al. 2014), our participants did not express feelings of frustration with the need to wait for appropriate care. This may be explained by the fact that participants were waiting in hospital and may have perceived themselves already receiving needed care. Yet it is acknowledged that waiting in hospital unnecessarily is not an appropriate use of hospital resources (Canadian Health Services Research Foundation 2011; Zhang et al. 2012). While it is accepted that the healthcare system cannot be expected to provide immediate access to all services, it is not unreasonable to anticipate reasonable access to health and social services. In the case of people waiting for long-term care services, what constitutes reasonable access needs to be determined. Similar to benchmarks established for cancer treatment, joint replacement and the other priority areas within the Canadian healthcare system, benchmarks for wait times for long-term care facilities and home care services across Canada should be considered. These guidelines must reflect the needs and the realities of the entire healthcare system along with those of individual patients and families. Benchmarks should include prioritization and urgency categories, thus helping to ensure resource allocation is based on need and not on financial resources or the ability of a family member to make regular contact with a preferred facility.

This study also highlights the financial implications of having to wait in hospital for long-term care. Remaining in hospital after being medically discharged by a physician is not a medical necessity and, therefore, meets the criteria of an uninsured hospital service according to the *Canada Health Act* (Parliament of Canada 2005). Hospitals have the authority to charge patients a daily or monthly rate to cover the cost of their hospitalization. This rate is equivalent to the rate of long-term care. In New Brunswick, the maximum daily cost for

long-term care is \$113 per day or about \$3,437 each month. For those who cannot afford this, the government provides a subsidy that includes the difference between this rate and the individual's Old Age Security and Guaranteed Income Supplement (Province of New Brunswick 2015). Participants in this study readily accepted the per diem rate charged by the hospital, and many rationalized that this fee was comparable with what they would pay if they, or their loved one, moved to a long-term care facility. Yet, hospitals are not long-term care facilities and despite efforts to establish "transitional care units" or "ALC units," hospitals are designed to provide care that is fundamentally different than that provided in long-term care facilities (Ostry et al. 2004). Organizational supports that enable staff to provide quality care to older adults with long-term care needs are often missing in acute care settings (Nilsson et al. 2012). For example, New Brunswick long-term care facilities are required to provide rehabilitative, recreational and social activities, and residents must be provided the opportunity to have input into standards of care and the management of each facility through a Resident Council (Province of New Brunswick 2015). Unlike hospitals, parking in long-term care is provided free of charge. Yet, if fees comparable with long-term care are to be applied to people designated as ALC, efforts should be made to ensure they receive the full scope of services they have paid for. Hospital standards should be developed to guide administrators who are developing specialized units for the growing number of people who wait in hospital for alternate services.

Another important finding was the fact that people designated as ALC are sensitive to the fact that they are in a setting where they do not belong and they feel they are utilizing a resource that could be better utilized by others. For many, waiting in hospital for alternate services generated feelings of unworthiness for care. Many did not feel they deserved the attention of hospital staff and made a concerted effort to minimize the work they created for staff. While these actions may have reduced the time staff had to be with them, they likely led to deconditioning and functional declines (Boltz et al. 2012; Mudge et al. 2010; Zisberg et al. 2011). This underscores the need for staff to engage patients waiting in hospital in activities that promote function and independence. Knowledge and understanding about supporting function and independence among staff working in units designated for ALC is an understudied area that warrants investigation.

Another surprising finding was the fact that the many participants acknowledged that a care provider was aware of the challenges they faced living at home prior to the admission, but did not suggest changes in the care environment. Of the nine participants who were receiving formal home supports prior to admission, only one did not acknowledge any unmet hygienic, nutritional or social needs. Participants assumed that because additional supports were not introduced that their current situations were acceptable. A possible reason for the failure to recognize the need for additional supports is the fact that up to 80% of home care is provided by unregulated care providers (Berta et al. 2013). Unregulated healthcare providers follow a clearly defined plan of care developed by others (New Brunswick Nurses Association 2011). Although skilled in assisting with activities of daily living, they do not always have the skills

to think critically, modify plans of care or to advocate for needed services. Competencies and training standards are needed for this essential group of healthcare workers to ensure they have the necessary skills to support the work they are expected to perform.

It is also possible that healthcare workers did speak about increasing supports but participants did not understand what was being discussed. Similarly, it is possible that supports were offered and denied to the three participants who did not receive assistance at home but who described a living situation suggestive of need. Participants may not have understood that they may have qualified for publicly funded home care, or that additional home care could have been available at no cost. Healthcare workers need to recognize that those not directly involved in the health sector may have difficulty discerning services available, and understanding the different roles and terminology used within healthcare. Many were unaware of the differences between home care, assisted living and long-term care; still others could not identify the government department/agency to contact to request community-based supports. Finally, care must also be taken to ensure that discussions surrounding ALC are not framed in a way that casts blame on the patients themselves. The issue of ALC should be presented in a way that acknowledges the difficulties and challenges related to limited access to long-term care and the effects that this has on everyone including patients, families, health and social services.

There are a number of limitations with the current study. The use of a convenient sample limits generalizability of findings. The inclusion of only English-speaking patients who could provide informed consent precluded those with cognitive impairment or non-Anglophone from participating. A recent study conducted in the province where this study took place reported that 63.6% of people designated as ALC had a diagnosis of dementia (McCloskey et al. 2014). It is possible that patients who did not meet this study's eligibility criteria had very different experiences that are not reflected in these findings. Reliance on interviews as the primary method of data collection limits information obtained to participant accounts of past and current events and functional abilities. Differentiation between actual and perceived abilities to perform activities of daily living was also not possible in this study. Data from patients and family members were analyzed together owing to the small number of patients and family members recruited into the study. Although it is recognized that both patients and families may each have a very unique perspective on ALC, it was not possible to analyze each group separately because of the small sample size. Future studies should consider alternate recruitment strategies, including the use of multiple hospitals, those with cognitive impairment and focusing separately on patient's and family's perceptions.

Finally, knowledge about the patients' length of stay – both the number of acute care days and ALC days – would have provided important information. However, this study design did not provide access to patient's hospital records, and therefore, information on acute and ALC hospital days was not available. The fact that six participants had also been transferred between two different facilities during the ALC stay further impeded the collection of

accurate data on the total length of hospital stay. Without these data, relationships between length of stay and experiences could not be made.

## Conclusions

Engaging patients and family members in discussions about being an ALC patient offers some insight into the personal perspective of the scope and depth of the ALC situation in Canada. A lack of long-term care services and the need for improvements in how hospital beds are utilized is a concern not only for hospitals but for patients and families as well. An important finding from this discussion is that much can be learned from ALC patients and families about how our health and social systems respond to the high demand for long-term care services. It is unclear from this study if home care alone is a viable solution to ALC in Canada. It appears that the complex ALC issue requires a multifaceted response that includes a comprehensive strategy of appropriately subsidized home care, case management that will assist individuals' transition across the care continuum in a timely manner, additional long-term care beds, a long-term care wait-list management plan that allocates resources based on clearly identified indicators and the development of best-practice guidelines for caring for people in hospital who are designated as ALC.

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